

TEAM JAROD • TEAM CALEB

THE SANFILIPPO HOPE INITIATIVE



This is Jarod and Caleb.

They love to do things like most boys their age...playing sports, riding bikes, swimming and having fun with their family, but their bodies harbor a deadly secret.

In 2011 Jarod and Caleb were diagnosed with **Sanfilippo Syndrome**. There is currently no cure, and no viable treatments have been discovered. BUT, we have a chance to fight this fate! We need to raise awareness of the disease, promote research that could lead to possible treatments, and ultimately find a cure. Children with this horrible disease should be spared the lifetime of pain and suffering that they are currently facing.

The **Sanfilippo Hope Initiative** was created to do exactly that. With your help we can offer assistance to families of individuals with Sanfilippo Syndrome, promote research, raise awareness and join together with other grassroots organizations to FIND A CURE!

JOIN OUR TEAM!



Volunteer/Donate/Get Involved!
SanfilippoHopInitiative.org
TeamJarodTeamCaleb.org
Find us on Facebook!

What is Sanfilippo Syndrome?

Sanfilippo Syndrome is an ultra-rare genetic disorder that occurs in approximately 1 in 70,000 births. It is caused when two parents unknowingly pass down a mutation of the same gene, causing a deficiency in, or lack of, an enzyme needed to break down a particular cellular product called **Heparan Sulfate**. When Heparan Sulfate is not recycled properly it slowly builds up in cells throughout the body and brain until they are no longer able to function, causing progressive damage. Children with Sanfilippo Syndrome are born seemingly healthy and usually don't exhibit symptoms until their preschool years. As they grow older, they commonly experience cognitive impairment, hearing loss, short stature, joint stiffness, hyperactivity, aggressive behavior, poor attention span, speech and language delay (and eventual loss), sleep disorders, digestive issues, vision impairment, enlargement of organs, seizures and loss of all motor capabilities. By the end stage of the disease children are extremely handicapped and are no longer able to walk, talk, feed themselves, swallow... survive.